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| Bill Number: | S. 1011 Amended by the Senate on March 15, 2022 |
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| Author: | Senn |
| Subject: | SC Parkinson's Disease Research Collection Act |
| Requestor: | House Medical, Military, Public, and Municipal Affairs |
| RFA Analyst(s): | Tipton |
| Impact Date: | April 22, 2022 |

Fiscal Impact Summary

This bill establishes the South Carolina Parkinson's Disease Research Collection Act and requires the Medical University of South Carolina (MUSC) to establish a system, including a database and advisory committee, for the collection and dissemination of data on Parkinson's disease and related parkinsonism. The bill further establishes confidentiality guidelines regarding Parkinson's disease data collected under this program and takes effect twelve months after approval by the Governor.

This bill will increase General Fund expenditures for MUSC by approximately \$150,000 beginning in FY 2022-23 for the establishment and maintenance of the Parkinson's Disease Database, salary and fringe for an additional Database Manager, and estimated expenses related to the advisory committee.

Explanation of Fiscal Impact

Amended by the Senate on March 15, 2022 State Expenditure

This bill establishes the South Carolina Parkinson's Disease Research Collection Act and requires MUSC in conjunction with the Parkinson's Disease Database Advisory Committee to establish a system for the collection and dissemination of data on Parkinson's disease and related parkinsonism. The bill establishes the Parkinson's disease database under direction of the Chief Executive Officer of MUSC who may enter into contracts, grants, or other necessary agreements for the purposes of data collection. This bill requires every patient in the state diagnosed with Parkinson's disease or related parkinsonism be notified by the diagnosing physician about the database and the opportunity to participate in data collection activities. If a patient declines to participate in detailed data collection, physicians are required to report the mere incidence of the case of Parkinson's disease to MUSC under this bill. The bill requires MUSC to provide notification of the mandatory reporting requirements directly to associations representing physicians and hospitals as well as the Board of Medical Examiners at least 180 days prior to the reporting deadline. MUSC must also include this notice on its website.

The Parkinson's Disease Database Advisory Committee is established to assist in the development and implementation of the database and to support data collection and

dissemination activities. The committee must include one general neurologist, one movement disorder specialist, one primary care physician, one physician who practices clinical informatics, Parkinson's patients, public health staff, population health researchers familiar with such databases, Parkinson's disease researchers, and anyone else MUSC deems necessary.

The bill further establishes confidentiality guidelines for MUSC regarding Parkinson's disease data collected under this program. MUSC must maintain the confidential information securely and promulgate a coding system to remove the confidential information when under review by non-privileged persons. The bill further provides the conditions under which MUSC may enter into agreements to furnish data collected in the database to other state, federal, or local agencies, officers, registries, or researchers pertaining to Parkinson's disease. This bill takes effect twelve months after approval by the Governor.

MUSC indicates that the establishment of the Parkinson's Disease Database and any corresponding equipment as well as mileage, per diem, and subsistence expenses as a result of the Parkinson's Disease Database Advisory Committee will total approximately \$75,000 annually. In addition, MUSC reports that a Database Manager would be required to oversee the implementation of the database and assume the technical responsibilities of maintaining and managing the data. This 1.0 additional FTE will incur annual salary and fringe of \$75,000. Therefore, this bill will increase General Fund expenditures for MUSC by approximately \$150,000 beginning in FY 2022-23.

State Revenue N/A

Local Expenditure N/A

Local Revenue N/A

Frank A. Rainwater, Executive Director